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Taking long term care from crisis to thriving in the time of COVID-19

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Norwood: Joanne, it's good to connect with you. I've been a long-time fan and follower of your work. I'd like us to reflect on how COVID-19 is exposing deficiencies in our current long term care system here in the U.S. and how we might be part of shaping a better future – you from your perspective as a geriatrician, hospice physician and advocate for innovations in long-term care and me from my perspective as a medical anthropologist and researcher on long term and end of life health policies. If you're game to try, I'll kick us off.

About three years ago, I read a book that basically predicted the crisis period we are in today. The book is *Generations* (1991) by [Strauss and Howe, 1991](#) and they used historical data dating back to the 16th century and developed a theory that each generation belongs to one of four types and that these generation types repeat in a generally fixed pattern, ultimately ending in a period of secular crisis. According to the authors, Baby Boomers who are described as idealist, moralistic- and action-driven are leading us during this current crisis and it is only something akin to a world war or a cultural revolution that can reset us. The last crisis period was 1925–1942 and included the Great Depression and World War II, before that it was the U.S. Civil War and the fight over slavery.

According to Strauss and Howe, crisis periods usually occur every 80–90 years, last about 20 years, and have over the centuries culminated in a period of peace then awakening, before generational tension builds again and we slide back into crisis. While it is not clear to me whether the data for their research was collected to fit their model or whether systematic data pulls resulted in this model, it seems their predictions are playing out pretty closely to how they described them back in 1991. I think we are indeed in a crisis period where extreme partisan politics, intolerance, inequities, and now a world-wide pandemic are exposing flaws we can no longer ignore in outdated policies

for policing, environment and climate change, healthcare and long term care, just to name a few. In this age of information, science and scientific method compete against the wealth of information and misinformation available via the web. Science is too often pitted, and sometimes losing, against the proliferation of unvetted information, compounded by the hysteria-provoking commodification of the 24/7 news cycle and the cacophony of reports of ever breaking news. What is reassuring, however, is to think of this as a predictable cyclical process where the current crisis period, if Strauss and Howe are right, will be followed by cultural change, peace, and potentially a new social order. Perhaps something better can rise from this time and just maybe we can come together to help shape what that something better looks like. Joanne, do you think this is a crisis period and, if so, what are the major problems that you see it exposing in how we care for our elders, especially as it relates to long term care in this country?

Lynn: Yes, we are in a crisis period, precipitated by COVID-19, but building on the fragile tower of dramatic increases in the gap between the well-off and nearly everyone else, with little manufacturing and an underpaid service economy. The powerful are able to keep widening the gaps and failing to deal with social issues – because they can. It is painful to read testimony from nearly 40 years ago about the oncoming aging of America. Most of the potential policy improvements were already in the testimonies back then. No one cared to act on them. Our policy horizon is about 2–5 years out. Some have said that Native Americans thought about the well-being of people seven generations into the future. Today, citizens and leaders in the U.S. too often don't even make it to seven years.

The aging of America has long been predicted – ever since kiddies toddled home from school in huge numbers in the 1950's and 1960's. We've collectively put our heads in the sand on this and other issues,

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including those central to the well-being of elderly people. We kick the can down the road so much that there must be a huge pile of cans somewhere!

Of course, part of the challenge is simply that our society does not have much experience with large numbers of people living well into old age – we misunderstand what it entails. We are learning, as the Boomers and their children take care of their older generations, that Medicare does not pay for long-term care and no one coordinates it. Much of our challenge is simply that we are stumbling onto the problem because our ancestors died so much more abruptly and so much younger – even just 50 years ago.

Norwood: When I look at the current state of long term and end of life care in this country, I largely see a medically-driven, badly coordinated system that has been hijacked by the siloed interests of numerous medical industries, leaving patients, families, and well-meaning health providers stranded in a system over which they have little say or control. I agree with you, it's a system designed for the 'haves' and leaving the 'have nots' to find their own way. Long term care is pretty good in this country if (or as long as) you can afford to pay for it. End of life care is in a strange wasteland between aggressive, expensive, and often futile medical intervention and when that is no longer viable there is hospice that can provide limited supports. We've developed such amazing medical triumphs and built health and long term care around these medical interventions, that we've forgotten the social side of health and well-being and left the 'caring' out of healthcare.

I am excited about what the *Patient Protection and Affordable Care Act* of 2010 has started in terms of transforming long term and end of life care. Since 2010, more and more providers are entering value-based payment arrangements where they are given greater flexibility to develop and coordinate care for their patients and instead of being paid (and incentivized) for quantity of services, they are being rewarded for better quality of care, improved health outcomes, while reducing cost or holding it constant. Under this system, social determinants of health – access to healthy food, transportation, affordable housing, social supports – all of these things that impact our health and well-being are being brought into the conversation. How well these supports are faring against a system that has been dominated by medical institutions and medical solutions, however, is not clear and when medical partners receive funding for coordinating and including social supports, how well is that really being integrated in the delivery of health and long term care? Also, the *Affordable Care Act* did little to transform long term care that I see. Do you have a sense of how long term care has fared since 2010?

Lynn: Medicare Advantage (MA) plans are supporting some social interventions, but only for their enrollees and only when doing so either encourages appropriate folks to enroll or when it saves money. This is not a solution to the crises in housing, food delivery, and personal care for the population. The fact that most areas of the country have multiple competing providers and insurers means that no one is attending to the needs of the community. A leader at Kaiser Permanente in California once told me that starting a program of screening for social issues in their medical service lines usually swamped the community's capacity within a few months. MA plans are both navigating patients to existing services and sometimes paying for them. But, when service capacity is limited, navigating to services means crowding out access to other important services and supports by persons who are not members of the particular MA plans.

We need to create an entity that takes responsibility for the well-being of everyone in a geographic area – all who are living with serious chronic conditions and disabilities. Then, the family that is stretched beyond capacity while trying to support the matriarch of the family is part of the cohort of concern, not just those who have a doctor and a Medicare Advantage plan. Such an entity needs data, authority, and some resources. Many countries have such an entity, but we don't. I think of this rather like a school board or a government-authorized public utility.

My team has been working on data that could be readily available from the Centers for Medicare & Medicaid Services (CMS) for every county in the country. A governing entity for eldercare could have a remarkable array of insight about their county from Medicare claims, Outcome and Assessment Information Set (OASIS, the assessments from Medicare-covered home care), and the Minimum Data Set (MDS, the assessments from all nursing home residents). Buttressed by data available from the census and other sources of information on social conditions, these could be remarkable resources.

What do you think of that possibility?

Norwood: I think that if there is ever a time to come together in a public-private partnership to leverage our data and what we have learned about how to re-organize healthcare, social supports, and long term care, that time is now. The *Affordable Care Act* laid a great foundation kicking off a re-organization of healthcare delivery from the payment system to leveraging real time data to allowing providers the flexibility to test real innovations, such as telehealth, use of nontraditional health workers, and a greater focus on social determinants of health.

A crisis period marks societies' collective dissatisfaction for outdated modes of thinking and connecting; it is a destructive period that paves the way for change but as Strauss and Howe point out, the generational pattern cannot guarantee necessarily a good outcome. If we can approach this period with some sense of strategy and purpose we may just be able to make the kind of transformation that leaders in health and long term care have been pushing for these many years. Tell me more about what changes you would like to see, especially for long term care in this country.

Lynn: First off, Americans need to have a life-span awareness, which is now remarkably missing. A century ago, childbirth and both agricultural and industrial work were dangerous, so people were generally very aware of death. Very few people lived into old age, and those that did were supported almost entirely by family and neighbors. It was an anomaly to end up in the "county home," because someone nearly always had room for a frail family elder in the vast array of descendants, relatives, and church people. We haven't quite matured into the realization that most of us will have an old age and at least half of us will have a substantial period of disability before dying. And most Americans think that some sort of arrangement is in place to provide for us, since it was not a pressing concern in the past. The relevant awareness is arising as the Boomer generation takes care of their parents, but much could be done to accelerate the cultural exploration of how to think about – and how to arrange ourselves – to accommodate our new reality.

Secondly, we need social arrangements that ensure that the vast majority of Americans have the financing they need when they are living past compensated work. Social Security needs to be more adequate and more adequately funded. And individuals need to feel some anxiety to save and to arrange their lives to have enough financial security. Still, the large gamble is long-term care needs. Around half of us will be able to provide for our own self-care until a final fairly brief illness and death. Many of the rest of us will need someone's help every day for less than a year. But some of us will be disabled for decades in old age. This is a classic situation for insurance, since no one can confidently predict their future and the costs are so variable. However, insurance to cover long-term care needs has become too costly for all but the wealthiest and they are least in need of it since assets are likely to be sufficient to purchase any required services. We need arrangements that would work for many "middle class" elders. A workable solution would limit how much a private citizen has to provide for, by having a social insurance scheme to cover long periods of long-term care (Cohen, Feder, & Favreault, 2018).

Third, we need to have age-friendly housing and environments. We need apartment housing with social services, one-floor small houses, and attachments to family homes suitable for living with mobility and visual impairments. We need sidewalks with curb cuts, transportation

services with help from the door and little waiting time outside, and age-friendly adaptations in businesses (including physician offices and clinics). With so many elders with some level of disability, we need to be reconstructing how the community should look and function.

Then we need a restructured workforce, especially of direct care workers. Family caregivers need financial supports, respite, training, and relevant knowledge. Paid workers need a living wage with benefits, career ladders, supervision, and respect. Workers in all roles need training in the special needs of disabled older people. Physicians, for example, need to embrace the obligation to work with the elder, family, and care team to develop comprehensive care plans and to be thoughtful about recommending treatment or diagnostic options that offer little gain and have substantial side effects.

And yes, we need to redesign nursing homes. Short-term care after hospitalization should be in hospitals, specific rehabilitation facilities, or hospices. Long-term care facilities will be needed by some, even where substantial support is available for living in the community. However, these can be smaller, home-like arrangements with the ability to respond to resident and family preferences, and mostly embedded in their communities.

Finally, so much about living well with disabilities in old age depends upon your community that it seems that the fundamental reform needed is for communities to begin to take responsibility for the performance of the eldercare arrangements that they happen to have, and to seek to improve them. For that to happen, communities need some way to monitor the local performance – e.g., how many elders are forced into institutions for lack of appropriate housing, how many must live with serious and often preventable adverse events like falls and pressure ulcers, and how many families are impoverished by long-term care costs or suffer excessive physical or emotional strain from trying to help their loved one. And the communities need to establish some entity that carries the responsibility to manage the eldercare arrangements, undertaking improvements and monitoring the effects. Most countries have such arrangements, but we do not yet. We should try it out as a large demonstration endeavor.

Maybe the fact that we are all in this together would motivate some of these changes. We do have the cultural background to work together – in barn building, road maintenance, childhood education, and dozens of other endeavors.

Norwood: We are all in this together and I hope this is the call to arms that we take up going forward. What I notice is that COVID-19 attacks us where we are most vulnerable – our need to connect and bond socially. Sociologist Thomas Scheff (1990) suggests that maintenance of social bonds is a basic human urge and you can see that even with the threat of death and chronic disability imposed by exposure to COVID, people cannot help but to seek out social connection.

How can we transform this global and massive disruption into something positive? I think we can do that by using the heart-wrenching stories of COVID deaths, especially in nursing facilities, to help transform our health and long-term care systems into something that brings the concept of “caring” back as a unifying concept. Let's build a long-term care system that better allows our family and friends to maintain their important and life-affirming social bonds. Let's build a home- and community-based long term care system that promotes social connection and those relationships that sustain us, especially as aging and chronic disabilities limit our ability to participate in key social activities, such as sharing a meal, attending church, or doing errands.

I would like to see us build a long-term care system around the concept of gift exchange. Sociologist Marcel Mauss (1967) suggested that gift giving is more than a voluntary act of charity; it is a process that binds us together in social, moral, and economic ways and for every gift given, a relationship is fostered. Even a simple gift of listening to someone talk about their day or helping prepare the evening meal sets off a relationship exchange and that in turn feeds into our identity, our sense of value and worth.

Our current long-term care system is built on an institutional-medical model that prioritizes sequestering disabled and older Americans away in nursing homes for health-monitoring and safe keeping, largely severing people from their social resources and providing little opportunity for socially healthy gift exchange. What if every long-term care program or facility instead was built around the concept of fostering person-directed gift exchange? If someone enjoys attending church and can no longer do so, how can we bring what they enjoy about the church to them so they can both give and receive what they most love in that church experience? If someone got a lot of their social worth from making dinner for their family throughout their lives, how can we build a long-term care environment that helps them continue to share what they love? For each person, what constitutes gifts that matter will differ. In other words, what they value and who and how they connect with others is personal and so any system built on this concept of gift exchange must be derived from and by that individual.

Person-directed gift exchange requires first and foremost a dialogue with the person about what they value. Given the massive social disruption caused by the COVID-19 pandemic, we need to start by opening up this dialogue. What do people living in long-term care right now fear; what are their hopes; and what do they value? Once you know what someone cares about, then you can brainstorm about how to best meet that need. COVID-19 work-arounds I've seen include building stronger phone relationships, using video platforms instead of in-person visits, bumping elbows instead of hand shakes, striking up deep conversations with strangers, more sharing via social media, and building up stronger inner circle relationships. I'm sure there are many more creative ways people are coming together during these difficult times.

The pandemic will eventually pass and this crisis period will eventually end, and when we get through this I'd like to see us care for each other in new ways that affirm our sociality and our humanity. This period of crisis is giving us an opportunity to think outside the box for innovative solutions. No crisis period, however, is a total break from the past; it is instead the promise of a new social order that builds on what we collectively value from our past. Shared values are what unites us, and in this period of upheaval we will need to identify what we care about and use it to help us negotiate this period of destruction and change. No one society collectively shares a set of values equally – as you can see so clearly delineated by the Me Too and Black Lives Matter movements, but we do have core values that shape how we see ourselves in relation to others. It's time now to talk about what we collectively care about and use this crisis period to build a new path forward for our families and neighbors.

Joanne, my last question for you has two parts. First, what research areas do you think need to be investigated most urgently to move us forward? And, second, if you had one thing you could recommend to our leaders in government to help move long-term care to a better place in this country, what would it be?

Lynn: We are so woefully underinformed. We need research even on what would be the basics in almost any other field. So much of what happens in old age depends upon your community – the housing, the workforce, the supportive services. But we have no way to characterize the performance of local care systems. And we don't really know what counts or how to measure it in long-term care. How do you know whether your community is doing a good job? Or what is most needed in order to improve? Yet, the most important thing is urgency. The issues are just going to become harder and harder to deal with over the next two decades. So – we need to work on financing, housing, supportive services, monitoring and management of performance, and workforce NOW. They are tough issues, and it will require substantial leadership to enable the public to learn what is at stake, but taking action right away is what matters. Kicking this can down the road is like kicking a hand grenade. You might get away with it for a while, but eventually it will result in destruction.

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